Diabetes Care and Mental Illness: The Social Organization of Food in a Residential Care Facility

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ABSTRACT

OBJECTIVE: To explore the social organization of food provision and dietary intake in seriously mentally ill people with diabetes who reside in a for-profit group home.

METHODS: Institutional ethnography was used to explore diabetes-related care practices among 26 women in a rural residential care facility in southern Ontario. Semi-structured, in-depth interviews were conducted with residents with diabetes, care providers, field workers, and health professionals. Observations and document analysis were also used to understand the lack of congruence between diabetes guidelines and the possibilities for diabetes management within the confines of group home care.

RESULTS: Although it was mandated in group home guidelines that "Health Canada's Eating Well with Canada's Food Guide" (2007) be followed, menus were planned within the context of a limited food budget of approximately \$1.91 per day per resident. Group home policies regulated systems of safety, reporting, and financial accountability, but not health promotion. Inspections carried out by the Public Health Department focused primarily on food safety during handling, preparation, and storage, and compliance to regulations regarding environmental cleanliness and infection control.

CONCLUSION: Resource rationing found in group home care exacerbates illness in an already marginalized group. Financial support is required to enable provision of healthy food choices, including dairy products, fresh fruits, and vegetables. Additional support is required for care of co-morbid conditions such as diabetes for associated food costs and education to improve outcomes. Group home policies must take into consideration health threats to this population and give primacy to health promotion and illness prevention.

KEY WORDS: Diabetes; dietary intake; serious mental illness; group home care; institutional ethnography

La traduction du résumé se trouve à la fin de l'article.

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While diabetes affects 6 to 8% of the general population in Canada,¹ people with serious mental illness such as schizophrenia or mood disorders have 2 to 4 times greater risk of developing diabetes due to genetic predisposition.² This risk is heightened by the widespread use of atypical antipsychotic medications, which are associated with dramatic weight gain, the onset and worsening of diabetes, heart disease, hypertension, and lipid abnormalities.³ Deaths related to heart disease associated with overweight and obesity are higher in the mentally ill.⁴ Diabetes is associated with earlier mortality; lifespans may be shortened by as much as 13 years in the general population.⁵ However, this is a much greater problem in people with serious mental illness, whose lifespans are shortened by as much as 25 years: high rates of morbidity and mortality in the mentally ill are linked with preventable diseases such as diabetes.^{6,7}

Mentally ill adults residing in group homes are faced with additional conditions, including budgetary restrictions and lack of pertinent information, which exacerbate risk and impede diabetes care and outcomes. In a community-based study of 1,123 people who were being treated for schizophrenia (of whom 78.7% resided in supportive housing), 43.2% showed evidence of prediabetes or diabetes.⁸ Although type 2 diabetes, which accounts for 90% of the cases, is largely preventable with lifestyle modifications such as weight loss and physical activity,⁹ there is little or no research that explores if and how these modifications are practiced in the group home context. Such studies are needed in view of the personal and associated treatment costs to afflicted residents of group homes.

The reported study is part of a larger project that used an institutional ethnographic approach^{10,11} to understand the social organization of diabetes care in a rural group home for people with severe mental illness. Institutional ethnography¹⁰ facilitates a rigorous analysis of the social relations that shape diabetes-related care and outcomes. In institutional ethnography, three tasks are paramount to inquiry: focusing on work practices, identifying textually mediated discourses, and mapping social relations.¹⁰ The term 'work' refers to "...anything that people do that takes time, effort, and intent" (p. 229),¹⁰ such as managing a chronic illness. These everyday situated activities are often coordinated by texts such as guidelines or policies that connect people in several different locations to central institutional processes.¹⁰ By focusing on social relations, it is possible to investigate institutional processes that create and sustain inequities to inform socio-political change¹⁰ such as health policy. In this article, we focus on dietary intake as an integral component of diabetes prevention and management.¹²

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METHODS

Setting

This ethnography was conducted in a for-profit rural group home for women diagnosed with serious mental illness, located in southern Ontario. One of the original Homes for Special Care (HSC) group homes, this location was purposely selected to facilitate our exploration of the evolution of group home care in Ontario, while focusing on diabetes care practices, which included transportation accessibility for medical appointments and quality of life opportunities. It is comparable to other group homes within the program across Ontario in that the per diem amount for each resident is the same, government support is not offered for care provider training, and the same provincial policies regulate all practices. Residential care facilities provide long-term and permanent residential care for vulnerable people with mental illness who require supervision or assistance with activities of daily living.¹³ In Ontario, they are funded by two programs: the HSC Program (supported by the Ministry of Health and Long-Term Care [MOHLTC]) and the Domiciliary Program (jointly supported by the Ministry of Community and Social Services and local governments).

Participant selection

There were 26 female residents, of whom 10 had a diagnosis of diabetes and 2 had prediabetes. Inclusion criteria for the residents were as follows: 18 years of age or over, a diagnosis of serious mental illness, and currently living in the group home. Inclusion criteria for those providing and overseeing care were as follows: experience working in or affiliation with the group home, and knowledge of the day-to-day processes of the home. All residents were invited to be involved in observational studies, along with 2 care providers and the home operator.

Data collection

Once ethical approval was obtained from the University of Toronto Research Ethics Board, informed consents were read and signed by participants. Eight of the 10 resident women with diabetes, 3 care providers, 1 family physician, 3 field/social workers, the home operator, and Social Night coordinator participated in semi-structured interviews conducted by the first author. Interviews were between 0.5 to 2 hours in length, audiotaped and transcribed verbatim, and pseudonyms were added to protect anonymity. In institutional ethnography, interviews are organized around the notion of work, especially how the participants' activities are connected to others' activities, which are coordinated in multiple sites over time and place.¹⁴ Ethnographic observations, which included care providers and 25 residents, were conducted over a 12-month period by the first author, each ranging from 1 to 8 hours in length, totaling 200 hours. By asking the question, "What is going on here?" and observing specific features of the social situation, we gained in-depth insights.¹⁵ Observations facilitated exploration of "the 'social' in motion" (p. 60),¹⁶ because social relations are situated in an actual time and place, and are ongoing rather than static. Detailed fieldnotes, taken during and after observations, were used to capture and preserve understandings gained through deep immersion that enabled thick description of group home life.¹⁷

Analysis

In institutional ethnography, interviewing, observation, and documents are used as data to investigate how people's local experiences are tied into institutional processes in order to discover how things happen as they do.¹⁸ The mapping of social relations starts with people at the local site, but continues to follow the data outward to distal organizations, like ministries or professional groups that are active within the problem of interest.¹⁹ The research started with illness-related experiences of the women residents living with diabetes and providers' work practices, and sought to understand how they were shaped by intersecting, but at times contradictory, policies regulating group home care and diabetes care provision.

Texts, because they are replicable, contribute to the coordination and standardization of professional and organizational interests when people interpret and enact them across different times and locations.²⁰ The coordinating effects of texts were analyzed by uncovering sequential work activities organized by documents that were imbued with institutional interests and discourses.¹⁰ Three regulatory texts contain policies and licensing regulations that coordinate group home care: the "MOHLTC: Operating Guidelines for HSC",¹³ the Residential Home Report,²¹ and the Hostel Compliance Checklist.²² Further texts were analyzed that are used by agencies such as the Public Health Department to monitor aspects of group home care.

RESULTS

Observation at mealtimes captured rich details about the social organization of food provision in the group home. Everyone, including the residents, engaged in the work of economization to ensure supplies were rationed and waste was avoided. As the following vignette suggests, mealtime practices were the nexus of multiple activities and influences.

At 4 p.m. the care provider rings the bell and women enter the kitchen to either take a seat, or to help by, for example, getting out silverware for their table. Each table is equipped with a bottle of hand sanitizer, and every woman uses it before eating. Peggy takes responsibility for this task at her table, and puts a squirt in each woman's hand. I am sitting beside Anne, a resident with diabetes, who tells me that her parents treated her to lunch today at a local Chinese food restaurant. She whispers that she "...had a piece of cake too." The care provider takes a big box of uncooked spaghetti, and puts enough for 26 women into a big pot of boiling water. When the spaghetti is ready, she scoops up noodles on each plate, puts on the sauce, and adds parmesan cheese for those who want it. She also serves Caesar salad, which was prepared by residents beforehand, along with a single-serving package of salad dressing. Meanwhile, Peggy hands out one roll to each woman. Peggy then takes the large rectangular tub of margarine and has each woman take out a small amount, as she reminds them to not take too much. Within 10 minutes everyone is enjoying their meal. One woman takes a roll and asks, "What're we having for dessert?" The care provider shows them the leftover Halloween treats, which will serve as tonight's dessert "...because they need to be used up."

A specific amount of spaghetti and salad was prepared to ensure all women were fed with minimal leftovers. Each received one dinner roll; salad dressing and margarine were portioned and rationed; and to avoid wastage, Halloween candy replaced the usual dessert. Budget work was not limited to food; it was part of every aspect of

group home care, including clothing, dental and eye care, programming, and transportation. The implicit government interest in cost savings that is imbedded in texts directing group home care created tensions in care provision, which was elaborated in interviews; these tensions are discussed in the following sections.

Organizing desire for food

Residents' interest in food was heightened in the absence of other vocational, recreational, and educational opportunities. Although activities such as an in-home craft program, shopping, bowling, Social Night, and movies were structured into the week, and attempts were consistently made to keep the women active, residents were often seen sitting in bedrooms and common areas between daily cleaning and mealtime routines. Residents and care providers linked inactivity with eating. "I find sometimes I get bored through the day so I like to eat" (Violet, resident). One care provider explained:

I'm not sure if it's because...they never have change (in routine), but they umm want to eat more...I don't know if that's part of the mental illness side of it or not, because I noticed some of them, when they're bored, even if they're not diabetics they're looking for something to do and it's downing the sugar, or bags of chips.

Food was also thought by care providers to substitute for quality of life experiences. "There's just not too much reward other than the three main meals, so that little trip to the convenience store to get something sweet or nice to eat just makes their day a little bit brighter" (Domiciliary hostel worker). Residents received a monthly amount of \$125.00, which was primarily used to buy cigarettes, and indulge in treats and fast-food items. These issues complicated the management of diabetes.

Family members offered novelty foods to allay feelings of guilt or remorse for having placed their relative in a group home. "Family members...know they're diabetics but they wanna make them happy and feel guilty...that they've placed them in these settings. So when they take them out they want to spoil them" (home operator). Generally, families offered meals or treats that were the residents' favourites rather than what was considered healthy. This placed diabetes management in tension with familial emotional complexities.

The group home physician stated that 20 out of 26 residents were prescribed atypical antipsychotic medications, which are associated with increased appetite.^{2,3,23} Care providers found it difficult to manage the residents' frequent complaints of hunger. "I don't think it's the diabetes. I think it's more the psych issues causes these massive appetites...it becomes a real issue because they're hungry and one actually thinks I'm trying to starve her...She weighs 180 pounds...she looks at you like you're this monster when you can't...fill her up" (home operator). Controlling food consumption is difficult if residents can never reach satiety, especially if the women cannot easily distract themselves with other activities due to lack of available options.²⁴ This issue was complicated by the tight food budget; healthy and substitute foods for those with diabetes could not be freely offered.

Textual organization of nutrition

To further illuminate the textually based organization of eating and diet in the group home, inquiry turned to analysis of diabetes practice guidelines,¹² group home care documents, and texts stemming

from policies such as Public Health inspection reports to see how they addressed dietary intake as an essential component to health and well-being in this population.

The home operator was paid a per diem amount of \$47.75 per day for each resident. The MOHLTC funding formula was outlined as follows: 59% for administration and program support services, 4% for raw food, and 37% for accommodation (p. 33).¹³ Drawing attention to food provision, according to this formula, \$1.91 for each resident per day was allotted. To reduce cost, economy grade food was bought in bulk, sale items were purchased in large quantities, and wholesale companies were used. To further reduce cost and confusion, the same meal was prepared and served to everyone, rather than tailoring to individual needs or preferences. Although cost savings was factored into decision-making regarding food purchasing and menu development, according to annual ministry-reviewed financial accounts, the home operator still paid out \$9.00 for food for each resident per day or five times the government allotment. The home operator paid out-of-pocket for food because she felt responsible and accountable. She further explained that she cares about the residents and that, "They have little else in their lives" (home operator). Extra expenses, including food items for people with diabetes, were not reimbursed.

Group home guidelines stipulated that 'Canada's Food Guide' (CFG) be followed.¹³ Diabetes Care Guidelines also recommended CFG for those with diabetes and prediabetes.¹² Recommendations for intake of essential nutrients in "Eating Well with Canada's Food Guide," (2007) were compared to the number of servings offered in each of the food groups in the six-week rotating menu plan followed in the group home. Instead of getting the recommended 14 to 21 servings of dairy products per week,²⁵ the residents were on average getting 6 to 7, which included the milk used for cereal, cream soups and puddings. The recommended number of fruit and vegetable servings per week totals 49 to 56.²⁵ Residents received approximately 8 servings of vegetables, and 2 servings of fruit (residents with diabetes received more fruit as a sweet dessert substitute), for a total of 10 "vegetables and fruit" servings per week. These findings are not surprising, because milk, fruits and vegetables are expensive and the funding is insufficient. Utilizing the annual regional survey for 2012, which is based on the "Nutritious Food Basket Guidance Document",²⁶ the weekly cost of eating healthily would be \$37.10 per person. This totals \$964.60 per week for the 26 residents in this home, which far exceeds the funding allotment of \$347.62 per week. Household food insecurity is more prevalent in those with diabetes and is associated with lower consumption of fruits and vegetables and lower levels of physical activity,²⁷ thus it affects diabetes management.

In order to align with the policy that stipulates three meals plus snacks must be offered,¹³ the home operator provided three meals (two with which dessert was served), plus two snacks per day. People with diabetes require regular meal spacing and snacks are often incorporated into diabetes regimens to maintain consistent blood glucose levels.¹² However, the women ate frequently, and of concern was the amount of carbohydrates and fat that they consumed, which increased the likelihood of weight gain. The home operator complied because license renewal was contingent on ensuring the mandated number of meals and snacks were provided. Field workers monitored adherence as part of their surveillance work, even with the knowledge that it led to health disparities.

"Really, you know, three snacks a day, it's too much...that's a lot of food in the day. I know that I can't eat that much and I love to eat" (HSC field worker).

Group home guidelines did not mention health co-morbidities and diabetes was not recognized as requiring added support. There was no funding within the programs for special food products. The HSC field worker reported, "As far as the food, you know, the diet cookies, the jams, the sugar-free puddings, whatever, a few homes will buy it. We really don't pay for the foods." The home operator paid for expensive diabetes food items. Anne, a woman with diabetes, used her money to purchase healthy food items, and was also budget-conscious. "(Home owner) buys me yogurt out of my PIN money... One time they had cherries on sale \$2.99 a pound...I bought 20 cherries so...it wouldn't cost me that much" (Anne, resident).

Staff education for the care of chronic conditions such as diabetes was not supported in these housing programs. The per diem amount was not sufficient to allow for the hiring of regulated health professionals, and the unregulated care providers, who were mandated to have First Aid and CPR, as well as Food Handling Safety certificates, were not to take responsibility for medical management. "Medical conditions, they don't educate us on that. So we have to go and find our own...and a lot of the information unfortunately that we're given doesn't apply to the homes because of the cost factor" (home operator). All participants, including the residents, echoed the need for relevant nutritional and other diabetes-related information. In this home, the operator and staff sought out information and used experiential knowledge in their diabetes care practices. However, as reported by the home operator and HSC field worker, diabetes was managed differently across homes, with some operators refraining from illness management, leaving the afflicted residents to struggle on their own. Other operators did not accept people with diabetes due to the added responsibility, liability risk, and associated costs.

Group home guidelines prioritized hygiene, fire safety, and financial accountability above health promotion and illness prevention.¹³ Food safety during handling and storage, infection control procedures such as proper hand washing, and environmental cleanliness and safety were the primary focus in Public Health inspection reports. Group homes are highly regulated and monitored for compliance and work activities are organized to align with inspection criteria. For example, staff held food safety certifications and everyone followed health and safety rules outlined for food handling and storage, sanitation of dishes, and hand washing. As noted in the vignette, all residents used hand sanitizer before eating, and care was taken to serve food quickly to avoid risk of temperature-related bacterial growth. However, nutrition as an integral component to promoting health, preventing illness, and managing medical conditions, like diabetes, was not found in the 'Food Safety Inspection Report,' nor was it included in the inspection process. Nutrition is also omitted from the "Ontario Public Health Standards and Protocols," which are meant to direct public health programming.²⁸ These intertwining, textually based social relations all contributed to disease-perpetuating conditions and inequities in health opportunities.

DISCUSSION

In this study, we focused on food provision and discovered the potential for overarching social relations of resource rationing to

exacerbate illness in this already marginalized group. Further, diabetes guidelines do not offer tailored suggestions for dietary management in impoverished groups or for those placed in residential care. Home operators of for-profit group homes are paid \$1.91 per resident for food provision. Nutritional recommendations, outlined in best practice guidelines and mandated in group home care guidelines, cannot be met. The diet was high in carbo-hydrates and fat, and lacked dairy products, fresh fruits and vegetables, and fibre, a finding similar to that of other studies reporting on diets of the seriously mentally ill.²⁹⁻³¹ However, this ethnographic study builds on previous research that utilized self-report data^{30,31} by investigating not only what residents reported about their diet, but how food is socially organized as part of diabetes care provision within the constraints of group home care. Illuminated were the suboptimal conditions for diabetes management that resulted from government interests in cost containment.

Inadequate funding for food increased residents' risk for development of diabetes. Risk could be further intensified by the women's low levels of physical activity, which were similarly reported in other studies exploring exercise in the mentally ill.^{4,32,33} We further discovered that sedentary lifestyles were also socially organized by government cost containment interests.²⁴ Added complications were medication-induced increased appetites, weight gain, and diabetes as a side effect of atypical antipsychotic medications, which are recommended in best practice guidelines. In this study, we also found that food, serving as a source of pleasure in the absence of other quality of life opportunities, was given a heightened significance by families, residents, and those overseeing care, which created further tensions in diabetes prevention and management.

Some group home policies were illogical or contradictory. Ironically, regulations stipulated strict surveillance of cleanliness, and fire and food handling safety processes, while neglecting other health threats, such as diabetes. Further, the policy stipulating provision of a minimum number of meals and snacks prompted home operators to comply by resorting to more affordable foods that are higher in carbohydrates and fat. This leads to weight gain and works against diabetes care efforts. In addition, unregulated care providers, who comprise the majority of group home workers due to insufficient funding to hire regulated health providers, are not required or supported to attain formal education for medical care provision.

To conclude, adults with serious mental illness who reside in government-regulated for-profit group homes are faced with numerous social forces that combine to create multifaceted barriers and constraints to the prevention and management of diabetes. The findings indicate an urgent need for Ministry financial support for food provision to meet nutritional requirements, and additional support for food items for those with diabetes. Policy amendments that give priority to health promotion, illness prevention, and medical management are required. Amended policies include government written commitment to financially support quality of life opportunities, and to provide support for the prevention and medical management of co-morbid conditions, like diabetes. Further, the linking of medical and psychiatric care in diabetes guidelines is required so that clinicians can recognize social and health inequalities and provide sensitive services to this high-risk, vulnerable group.

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RÉSUMÉ

OBJECTIF : Explorer l'organisation sociale de l'approvisionnement en aliments et les apports alimentaires de personnes diabétiques gravement atteintes de maladies mentales vivant dans un foyer de groupe à but lucratif.

MÉTHODE : Nous avons utilisé l'ethnographie institutionnelle pour explorer les pratiques de soins du diabète chez 26 femmes vivant dans un établissement de soins résidentiels en milieu rural dans le sud de l'Ontario. Nous avons mené des entretiens semi-directifs approfondis avec des résidentes diabétiques, des fournisseurs de soins, du personnel de terrain et des professionnels de la santé. Nous avons aussi eu recours à l'observation et à l'analyse documentaire pour comprendre le manque de concordance entre les lignes directrices sur le diabète et les possibilités de prise en charge de cette maladie dans le cadre des soins en foyer de groupe.

RÉSULTATS : Malgré les lignes directrices des foyers de groupe, qui doivent suivre les directives de l'ouvrage Bien manger avec le Guide alimentaire canadien de Santé Canada (2007), les menus étaient planifiés dans le contexte d'un budget alimentaire limité (environ 1,91 \$ par jour par résidente). Les politiques du foyer abordaient les systèmes de sécurité, de production de rapports et de responsabilité financière, mais pas la promotion de la santé. Les inspections menées par le Service de santé publique étaient axées principalement sur la salubrité des aliments durant leur manipulation, leur préparation et leur entreposage et sur la conformité aux règlements de propreté de l'environnement et de contrôle des infections.

CONCLUSIONS : Le rationnement des ressources observé dans les soins en foyer de groupe exacerbe les maladies au sein d'un groupe déjà marginalisé. Une aide financière est nécessaire à un approvisionnement en aliments sains, notamment en produits laitiers et en fruits et légumes frais. Un soutien supplémentaire est également nécessaire pour le soin des comorbidités comme le diabète, afin de couvrir les coûts des aliments et de la sensibilisation connexes afin d'améliorer les résultats. Les politiques des foyers de groupe doivent prendre en considération les menaces pour la santé dans cette population et accorder la priorité à la promotion de la santé et à la prévention de la maladie.

MOTS CLÉS : diabète; apport alimentaire; maladie mentale grave; soins en foyer de groupe; ethnographie institutionnelle